

# GLOBAL FEAST 2007



Global Feast: New South Wales (left), South Australia (centre) and Victoria (right)

Haemophilia Foundation Australia joined other international Haemophilia Foundations - Argentina, Iran, Nepal, Netherlands, New Zealand, Nigeria, Portugal, United Kingdom and World Federation of Hemophilia (Canada) for GLOBAL FEAST 2007.

Global Feast was initiated in 2005 by the World Federation of Hemophilia, with Australia participating from the start. The aim of the global event is to bring together the community and support people worldwide with bleeding disorders. It is as simple as inviting over friends for a meal and instead of asking them to bring a bottle of wine, ask them for a donation instead.

#### Events hosted:

- HFA staff hosted a 'Thai Night' to recognise our twinning with Thailand for their friends and families and raised \$325. Quiz questions about haemophilia raised awareness, and facts about Thailand were included in the quiz to keep to the theme for the night.
- Leonie Mudge from Royal Prince Alfred Hospital Sydney hosted a morning tea and raised \$50.
- Anne Jackson from Women's and Children's Hospital South Australia hosted a lunch and morning tea raising \$200 hosted a Mexican lunch and morning tea for the staff raising \$200. Although the lunch was a casual affair the food was lovely and it was fun!

- Peter Fogarty (HFA Board member and HFQ President) and his family hosted a high tea afternoon with family and friends.
- A family from the Bellarine Peninsula in Victoria hosted a dinner with family and friends and raised \$325.

Global Feast will once again be celebrated next year. We do hope that more people come on board for this simple event and support people worldwide with bleeding disorders.

People with bleeding disorders are lucky to receive the treatment and care they need. But, did you know that 75% of the bleeding disorders community worldwide does not have access to proper treatment and care? 

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14<sup>th</sup>

# Australian & New Zealand Haemophilia Conference Canberra 4-7 October 2007

bleeding disorders ~ achieving success to last a lifetime

[www.haemophilia.org.au](http://www.haemophilia.org.au)



HAEMOPHILIA FOUNDATION AUSTRALIA

**The 14th Australian and New Zealand Haemophilia Conference** is around the corner and it still isn't too late to register. The conference will be held in Canberra which is lovely in Spring and a perfect place for a family holiday following a conference.

You can see from the current conference program on pages 10 and 11 a wide range of issues and topics related to the impact of bleeding disorders will be covered and will be of interest to people who want to know more about what is happening in Australia and overseas, and how bleeding disorders might be managed better.

The conference will interest individuals and their families, health professionals and others who are involved with the bleeding disorders community. It is aimed at people with haemophilia, von Willebrand disorder and their families (including young people) of all ages, specialist health professionals (doctors, nurses, physiotherapists and counsellors from haemophilia centres around Australia and New Zealand), treatment product producers,

government officials and volunteers and employees of haemophilia foundations. We have already received registrations from people in all these roles from around Australia and New Zealand.

Speakers from around Australia and New Zealand will provide a range of perspectives on bleeding disorders.

We are delighted that Dr Kathelijin Fischer from The Netherlands where she works at the University Medical Center Utrecht, both as a pediatrician, and as an epidemiologist, has accepted our invitation to speak. She has a strong research interest in prophylactic treatment for severe haemophilia.

Patricia Cameron-Hill and Dr Shayne Yates are well known educators on stress and humour. Their careers as a nurse and doctor give them a special understanding of stress, its consequences and its cure. Their best-selling book "You won't die laughing" is read by many. They balance the funny side of stress with the serious side by including strategies for resisting and reducing stress.

Youth can attend all mainstream program sessions and some of these will be specifically geared to youth issues. Youth delegates must be aged 14 or over and will attend the conference sessions on Friday and Saturday and any of the workshops on Sunday morning. On Sunday, youth delegates will have an offsite activity at Pitch n' Putt golf.

For more information visit [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) or contact HFA on 1800 807 173. You can also register online at [www.haemophilia.org.au/registration](http://www.haemophilia.org.au/registration)

HFA values the support of:

#### Major Conference Patrons

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#### Special Conference Partner

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#### Conference Partner

Octapharma Australia

Supported by ACT Health

# CHANGES TO THE MANUFACTURE OF PLASMA DERIVED FACTOR VIII IN AUSTRALIA

Sharon Caris

Most people in Australia use recombinant factor VIII for the treatment of haemophilia A, however for clinical or other reasons, a number of people continue to use plasma derived factor VIII, BIOSTATE<sup>®</sup> manufactured by CSL Bioplasma.

In recent years, concerns have been raised about the theoretical risk of transmission of prion diseases such as variant Creutzfeldt Jacob Disease (vCJD) and there have been four cases of transmission by red blood cell transfusion in the United Kingdom where most vCJD cases have occurred.

Whilst there has been no known transmission of human transmissible spongiform encephalopathies (TSEs) such as vCJD being transmitted to humans through plasma derived concentrates worldwide, industry and regulators continuously review the steps which can be taken to enhance the safety of these products and lessen the risk that it will occur.

Risk models for plasma derived products consider both the experimental prion clearance capacity of the manufacturing process, and the plasma source. Based on risk modelling, the Transmissible Spongiform Encephalopathies Advisory Committee (then known as the Special Expert Committee on Transmissible Spongiform Encephalopathies) recommended in 2005 that additional precautionary measures should be undertaken in Australia to further reduce the theoretical risk of transmission of vCJD by plasma derived factor VIII, BIOSTATE<sup>®</sup> as it was manufactured at the time<sup>1</sup>. The additional step undertaken then was to restrict plasma for the fractionation of BIOSTATE<sup>®</sup> to donors who had not

travelled to countries where bovine spongiform encephalopathies (mad cow disease) and vCJD had occurred.

Since that time, a revised manufacturing process incorporating additional filtration steps has been developed by CSL Bioplasma to enhance the capacity of the process to remove experimental prions. This change to the manufacturing process was recently approved by the Therapeutic Goods Administration (TGA). On evaluation of the experimental prion clearance data associated with the additional filtration steps, the special donor restriction for plasma used for the manufacture of BIOSTATE<sup>®</sup> has been lifted and BIOSTATE<sup>®</sup> can now be fractionated from all suitable plasma donated in Australia. This also means the recent shortages of BIOSTATE<sup>®</sup> will ease somewhat.

Currently, plasma used for fractionating plasma derived therapeutics (and now including BIOSTATE<sup>®</sup>), is collected by the Australian Red Cross Blood Service under ongoing donor exclusion policies, which exclude potential donors if they have resided in the UK between 1980 and 1996 for a total (cumulative) time of six months or more, or have received blood transfusions in the UK since 1 January 1980.

CSL has advised HFA that there is no change to the appearance or storage conditions of BIOSTATE<sup>®</sup> with the new manufacturing process. For information about administration of plasma derived products please refer to the Product Information or Consumer Medicine Information or contact your haemophilia centre. **H**

#### Reference:

1. *National Haemophilia*, No 151, August 2005

## ERRATA

In the June 2007 edition of *National Haemophilia*, No 158, *The Hep C Review*, December 2006, published by Hepatitis C Council of NSW was acknowledged as the source of the article on CRS Australia Services. The article was, in fact, provided by CRS Australia for the Australia/NZ Haemophilia Social Workers' and Counsellors' Group and was published with the permission of CRS Australia. We apologise to Hepatitis C Council of NSW, CRS Australia and the Australia/NZ Haemophilia Social Workers' and Counsellors' Group for this error.

In the June 2007 edition of *National Haemophilia*, No 158, the article on Generic Medicines – the Myths and Realities by Jan Donovan, which was first published in *The Australian Health Consumer Issue 1* of 2006-07 was referenced incorrectly. The author's references in the text were not superscripted, and were printed just as numbers. The references at the end of the article should have been numbered 1 and 2. We apologise to Consumers' Health Forum of Australia for this error.

# HAEMOPHILIA AWARENESS WEEK

The theme, **Haemophilia ~ One Community, Many Faces**, aims to portray that haemophilia can affect people of all ages and experiences.

HFA and Haemophilia Foundations around the country work together to raise awareness about inherited bleeding disorders to the general community, community organisations and governments. A team of representatives from HFA and each of the State/Territory Foundations have developed a plan which will be implemented in the lead up to, and during Haemophilia Awareness Week in October.

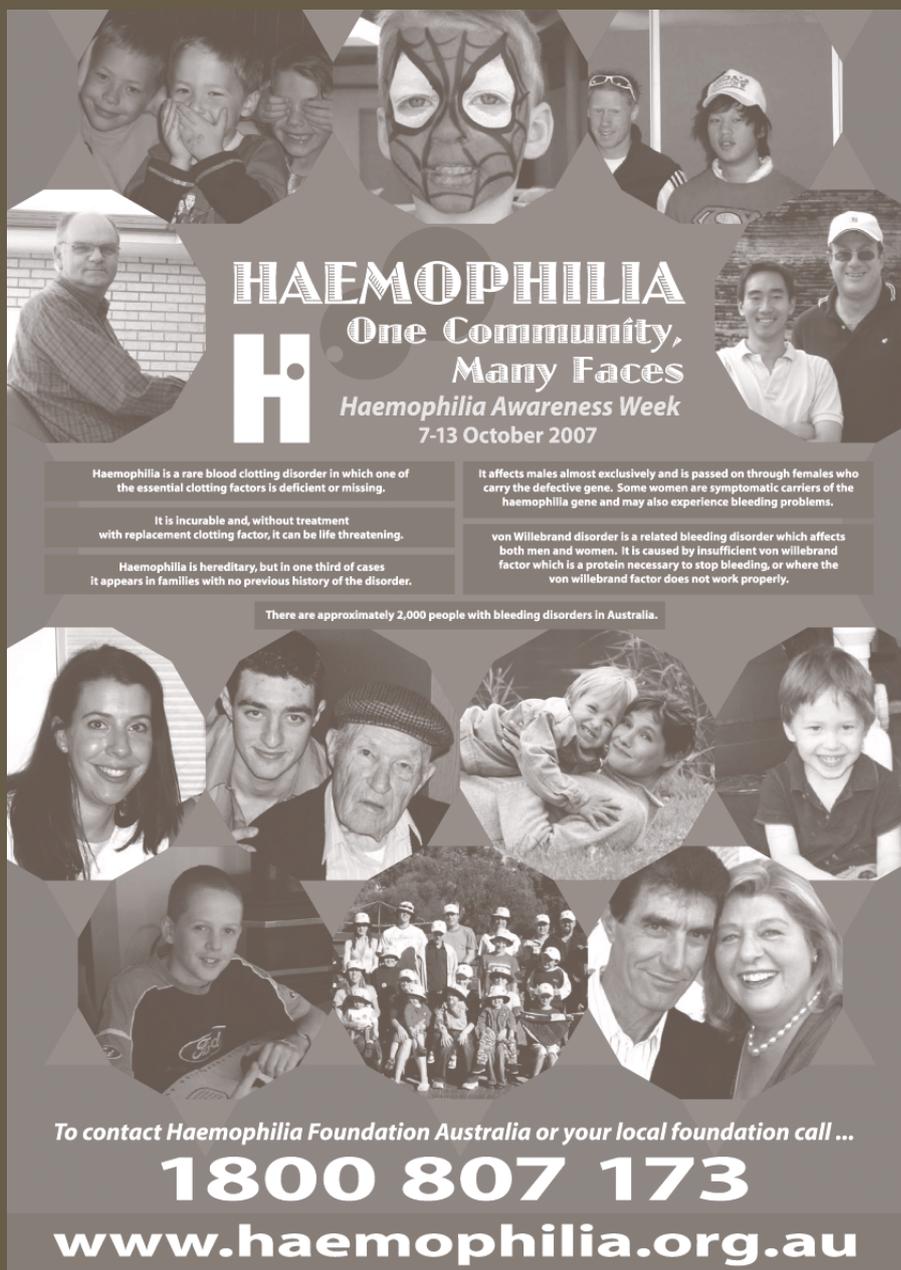
There are many ways you can help us promote Haemophilia Awareness Week ~

- Set up a stand in your workplace, school, hospital or library
- Hand out promotional items in your local area
- Assist your local foundation during the week
- Organise a casual clothes day at your workplace or school – try a Red and White Day in return for a gold coin donation
- Organise a luncheon, sausage sizzle or morning/afternoon tea

• Request your promotional items now!

• Balloons, Stickers, Posters and Bookmarks are available for distribution and there is a colouring in competition for children

If you would like to receive a promotional package, or are planning to run an event for Haemophilia Awareness Week contact HFA on 1800 807 173 or email [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) 



**HAEMOPHILIA**  
**One Community,  
Many Faces**  
*Haemophilia Awareness Week*  
7-13 October 2007

**H**

Haemophilia is a rare blood clotting disorder in which one of the essential clotting factors is deficient or missing.

It is incurable and, without treatment with replacement clotting factor, it can be life threatening.

Haemophilia is hereditary, but in one third of cases it appears in families with no previous history of the disorder.

It affects males almost exclusively and is passed on through females who carry the defective gene. Some women are symptomatic carriers of the haemophilia gene and may also experience bleeding problems.

von Willebrand disorder is a related bleeding disorder which affects both men and women. It is caused by insufficient von willebrand factor which is a protein necessary to stop bleeding, or where the von willebrand factor does not work properly.

There are approximately 2,000 people with bleeding disorders in Australia.

To contact Haemophilia Foundation Australia or your local foundation call ...

**1800 807 173**  
**[www.haemophilia.org.au](http://www.haemophilia.org.au)**



# GLOBAL PERSPECTIVE

*The following article was written by World Federation of Hemophilia staff in July 2007 and was featured in the Spring 2007 edition of "H.Link" published by Haemophilia Foundation Australia.*

## THE LONG JOURNEY OF MIRRIAM MOKWENA

As Africa struggles with HIV/AIDS, malaria, armed conflicts and other tragedies, the plight of people with haemophilia could easily be overlooked, were it not for WFH volunteers like Mirriam Mokwena.

The South African nursing sister adopted haemophilia care as her mission some 10 years ago when she found that many patients were often diagnosed or treated too late to prevent disability or early death.

"It's heartbreaking to see a child who'll never be able to walk again because his parents didn't know what to do," says Mirriam.

"Information is vital for haemophilia patients, so I began outreach training and education for people in the black townships and villages."

Conducting workshops and information sessions often involve long and sometimes dangerous travel. She's braved jungle tracks, dusty roads, and floods to meet patients and their families, who had frequently never heard of haemophilia.

"I organised intensive training in six provinces on the signs and symptoms of haemophilia, what treatment was needed and where to find it," says Mirriam. "Forget PowerPoint presentations where there's no electricity!"

Mirriam's communication skills were also valuable: "Local African people would open up to me. I was more like a sister to them. I spoke their languages and understood their

culture and background. Knowing their limitations and difficulties we worked together to solve their problems."

The outreach training paid off. Diagnosis of people with haemophilia increased and eventually more urban and rural hospitals in South Africa started to treat patients. But Mirriam saw there was more to be done, especially for patients who had crossed the border for haemophilia treatment in South Africa. Following up on their treatment and care took her to neighbouring countries such as Namibia, Lesotho, and Botswana.

"My role in outreach was extended when I joined the WFH Nurses Committee. We discovered that the biggest obstacle to care for people with haemophilia was the lack of information by health professionals." So, in 2002, Mirriam and her colleagues started a course in South Africa that provides haemophilia training for medical workers from across the continent.

"We touch so many people on this journey," she says. And those people touch others.

The sight of patients receiving treatment for their bleeds, with reduced joint damage and deformities has motivated nurses elsewhere to follow Mirriam's example.

"I was seen as a motivator by other nurses in the other countries, more nurses wanted to be like me, and do their jobs like me. I was also inspired when people with haemophilia and their families from other countries turned to me for help."

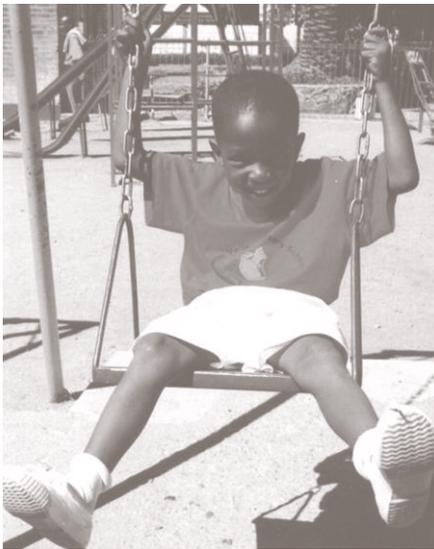
Mirriam does not hesitate when asked to sum up her years as a WFH volunteer: "I love my job. I've been a treater, an educator, an advocate, a sister, and a mother."



## ALBERTO PAREJA

Alberto Pareja is 19 years old and lives in Peru. Alberto's cervical hematoma was life threatening. As a teenager with haemophilia who also has severe inhibitors, specialised factor clotting concentrates were necessary to treat his bleeds properly. Living in Peru, where the average family earns US\$920 per year, Alberto's family had very limited funds to access the haemophilia treatment their son required. Thanks to a 2000 IU donation of factor from the World Federation of Hemophilia and the skill of Alberto's haematologist, Doctor Gloria Chumpitaz of Hospital Rebagliati in Lima, Alberto was able to receive the medical treatment he needed. He recovered well and now is able to return to school.

>>



## HOPE IN ZIMBABWE COMES IN SMALL PACKAGES

Ten-year-old Mthandazo Ian Bhebhe is like every other child, except he needs haemophilia treatment and often goes without it.

Bhebhe lives in Zimbabwe, a country devastated by civil, political and economic turmoil. Life expectancy is less than 40 years, according to recent UN estimates. Most children with haemophilia in the country remain undiagnosed and untreated. They do not live beyond their teenage years. Yet, there is hope for Bhebhe. He has a world of people who care for him, the haemophilia community.

Recently Bhebhe fell at school and injured his knee, which swelled to the size of a large grapefruit. Without available treatment, doctors gave Bhebhe morphine for three weeks and considered amputating his leg. The World Federation of Hemophilia responded quickly by delivering donations of blood treatment products to the Zimbabwean National Blood Transfusion Service, which determined that Bhebhe was the patient in most need of treatment. Within days, Bhebhe was able to walk using crutches. The week after receiving proper treatment, he went home. Although he continues to need crutches, Bhebhe is able to walk on his own from home to the bus stop and make his way to school. **H**

*Jill Smith is Haemophilia Coordinator at the Haemophilia Centre of WA at the Royal Perth Hospital (RPH) in Western Australia. She visited South Africa and Lesotho in June 2007.*

# A VISIT TO SOUTH AFRICA AND LESOTHO

*Jill Smith*

## Lesotho

As Lesotho is the Royal Perth Hospital haemophilia centre twinning partner I scheduled a visit to Maseru the capital, for a day's visit with the haemophilia team.

At the meeting Dr Grace Phiri, the director of haemophilia services, the two haemophilia nurses, physiotherapists and members of the Haemophilia Association of Lesotho outlined their activities for the year. The first project was to raise awareness of haemophilia by celebrating haemophilia day in April and giving presentations about haemophilia to pupils at a local school. The second activity was to visit hospitals in regional areas to raise awareness of haemophilia among staff. These presentations had been well received and attracted large numbers of staff.

Although there is still a pressing need to train staff from Lesotho in haemophilia care, especially doctors and physiotherapists, progress is being made on this. In addition, medical equipment which included a coagulation analyser, physio and

orthopaedic equipment from Perth, was donated to the haemophilia service in Lesotho. This shipment arrived shortly after my visit and was taken care of by the Rotary Club of Maseru.

## Haemophilia Nurses' Training Course, South Africa

This course is now in its sixth year and on this occasion it was held at Potchefstroom in the North West province. The course was attended by 34 participants. It was a very successful training course as all students passed. Next year the course will be held in Bloemfontein.

Sadly, this was the last training course for Mirriam Mokwena, the South African Haemophilia Outreach nurse. Mirriam has resigned to go to a new career direction. Her contribution to haemophilia care in South Africa, the region and globally is greatly appreciated and will be difficult to emulate. **H**



# JENNY'S GALLERY

Jenny Fitzpatrick-Frame



Opening my own art gallery and my home as a B&B has felt like an impossible dream. Coordination of trades people and material necessary for the renovations takes a fair bit of focus and time. Inside I'm full of excitement.

My congenital back problem has interrupted my employment several times so this dream will allow me to work from home and hopefully still bring in some income. Neil, my partner, an aged carer, says he makes a great Basil Fawty.

Three years ago I had not done any art at all. When I began I was impressed with what I could achieve. The joy and pleasure I get from painting flowers is two fold. Firstly, I love all aspects of gardening - planning, design, veggies, flowers – the lot. Secondly, because I am so inspired by my son, Mark. Without a family history it was a shock to have a child with severe haemophilia A and inhibitors. He also had corrective heart surgery at four weeks of age. Mark was the first child with haemophilia to die of HIV/AIDS in Australia. I had lobbied hard for better treatment and care in Tasmania and was partly involved with obtaining financial support for people with medically acquired HIV/AIDS. The Mark Fitzpatrick Trust Fund that was established lasted as long as Mark's short life – 10 years.

I would like to share with you why I decided to call my collection of art "Flowers from Heaven". What still amazes me about Mark was how accepting, brave and loving he was. On my 32nd birthday we had a

discussion about what heaven would be like. My version was that it would be full of beautiful gardens, flowers, trees, birds, butterflies and ponds – it would be a place of beauty. Mark added that all the animals and people would be friendly. We both agreed that was a good version of heaven. Mark said to me that day, "Mum, when I get to heaven, I'm going to pick you the biggest bunch of flowers." Then he asked with a worried frown, "How will I get them to you?" I replied, "You will be an angel in heaven, you will find a way." He asked me to promise him one thing – "Mum, I want you to promise me you will be happy." My response was, "I'll do my best, and I will create a beautiful garden wherever I go to remind me of you."

I never, ever realised that it would take me 15 years to find the gift and it was right there inside me.

The Gallery will open in October and will feature *Flowers from Heaven*. Contact HFA for further information on 1800 807 173 or [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).

Jenny's Gallery will be open 11am-4pm Monday-Sunday 7.30pm-9.30pm Saturdays.

727 Melrose Road, Melrose, Tasmania 7310 – 15 minutes south of Devonport. **H**



# WHAT IS HFA DOING ABOUT HEPATITIS C?

Suzanne O'Callaghan

## NATIONAL NEEDS ASSESSMENT

I am currently writing up the report on the HFA national hepatitis C needs assessment. A major part of the report is the section about focus group discussions on hepatitis C. In three states and Territories, people with bleeding disorders affected by hepatitis C and their families met with the HFA Policy Officer and the Haemophilia Social Worker/Counsellor to talk about the impact of hepatitis C on their lives and what their needs were. This is important evidence about what it means to have a bleeding disorder and hepatitis C.

This section describes common themes in the discussions and includes people's quotes and stories. People who took part in the focus groups will look over this section and comment on it before it is published. Many people in the focus groups said that before they came to the group, they felt like they were alone. They thought it would be helpful to other people with bleeding disorders and hepatitis C to hear their stories and know that there are other people with similar experiences.

What about the people who didn't attend the focus groups? The report will include a summary of HFA consultation with State and Territory Haemophilia Foundations and haemophilia health professionals. In the consultation we discussed what they knew about hepatitis C issues for all local members and what work still needs to be done. The local Haemophilia Social Worker/Counsellor and I looked closely at the transcripts of the discussions. We summarised the common issues in the focus groups but also looked at any other issues that come up for people affected by hepatitis C who did not attend the focus groups to make sure the report shows a balanced picture.

The report will be launched at the Haemophilia Conference in October 2007. Stage 3 of the needs assessment will be evaluating the work to date. We will be asking for feedback on the report.

- If you are affected by hepatitis C, do you recognise some of the experiences discussed in the report or has your experience been different?
- Have you seen any difference in hepatitis C information and services for people with bleeding disorders, or in people's attitude to hepatitis C in the last 12 months?

These questions will also be asked in focus groups in some States or regions that did not have focus groups earlier in the year.

## HAEMOPHILIA CONFERENCE

Part of the HFA national hepatitis C strategy is to provide information and education on hepatitis C to haemophilia health professionals. The 14th Australian and New Zealand Haemophilia Conference is a great opportunity to have experts to update us on the latest information around hepatitis C, and will be a forum for both members and health professionals. The conference program has been designed to cover some of the key questions for people with bleeding disorders:

- What is the latest on hepatitis C and treatment?
- How do people make decisions about treatment?
- What do young people with hepatitis C have to deal with when they are becoming young adults?
- How do young people tell their new partners about hepatitis C?
- How do you manage depression?
- What about stigma and discrimination? What do we know about it? What is being done to improve the situation in Australia?
- What have been people's experiences of being affected by hepatitis C and bleeding disorders in Australia?

This will be a very exciting time when we can compare notes and share ideas. **H**



## HEPATITIS C AWARENESS WEEK

During the focus groups several people said they thought the general public needed to be educated about hepatitis C to stop stigma and discrimination.

National Hepatitis C Awareness Week will take place between 1 and 7 October 2007. To raise awareness about hepatitis C in the general community, Hepatitis Australia (formerly the Australian Hepatitis Council) is co-ordinating educational activities around Australia.

The theme is "Hepatitis C: learn the facts". There are posters, and also postcards, bookmarks and stickers about preventing hepatitis C, discrimination and treatment. There is also information on the Hepatitis Australia web site - [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com). One

# FATIGUE AND ILLNESS

Dr Mark Swain

With many medical conditions – such as liver disease – fatigue can be a major issue. Dr Mark Swain explores why we feel tired when we're ill.

Brain function drives the fatigue in these diseases, even though all of them occur outside of the brain.

"When we become sick with the flu or a bacterial infection, we feel tired, as well as losing our appetite and so on," explains Dr Swain. "The body signals the brain to produce these symptoms or behaviours. It's important for us to conserve energy and not move around and do things – so we'll get over the illness and get back to normal. Unfortunately, with a chronic disease, we don't get over the illness. The stimuli to the brain keep happening. Our bodies try to adapt but they never fully do so."

Throughout his career as a physician and researcher, Dr Swain has attempted to improve the quality of life and health outcomes for people suffering from liver disorders. More than 100 known forms of liver disease affect everyone from infants to older adults. Liver damage can result from viruses, cancer, autoimmune disorders, alcohol, drug use, toxins, and obesity.

## LIVER PROBLEMS

Dr Swain studies, diagnoses, and treats such liver problems as hepatitis, cirrhosis, fatty liver disease, and liver cancer. He investigates the basic mechanisms of liver inflammation and the changes in neurotransmission within the brain that occur in the context of liver disease. He is especially fascinated by the effects of liver damage on symptoms in liver disease, particularly fatigue. Dr Swain studies how the liver might signal the brain, with the end result that the person feels tired.

Fatigue is the symptom most commonly mentioned by people with liver disease, but its cause is a puzzle. Since fatigue is an unspecific symptom (in other words, it can be caused by a variety of health problems), it is difficult to determine whether it is caused by the liver disease or by something else, or by a combination of factors. This is one reason why fatigue is difficult to study, understand, and treat.

## PERIPHERAL FATIGUE

Many people with very severe liver disease suffer what is called peripheral fatigue as a result of muscle atrophy. Patients with less severe disease often experience fatigue not related to muscle deterioration: that is, fatigue that

comes from changes occurring within the brain. The severity of the fatigue in these individuals does not relate to their liver function. This means that some people who have severe liver damage may not feel tired at all, while others with minimal liver damage may feel totally exhausted.

"Fatigue can be the main feature of many forms of liver disease, and can be anywhere from mild and trivial to completely incapacitating," explains Dr Swain. "The thing that's most difficult is that there's no correlation between the severity of the fatigue and the severity of the liver disease. Some people will say, 'If I have cirrhosis, why do I feel so good?' Others will say, 'Why do I feel so bad?' I think, inherently, some people are more tired than others because of the different ways individuals adapt to the signals which their bodies are sending to their brain." Dr Swain hopes that his research may someday allow physicians to better target the treatment of fatigue as a symptom, improving quality of life for patients with liver disease and possibly for those with other chronic diseases as well. **H**

important message is that the success rates of hepatitis C treatment have improved vastly – now at around 50-80%, depending on genotype. This message has been printed on the bookmark – you will find a copy of the bookmark in this issue of *National Haemophilia*. If you are looking for information that is more relevant to people with bleeding disorders, try also the hepatitis C section in the HFA web site – [www.haemophilia.org.au](http://www.haemophilia.org.au).

Hepatitis C Awareness Week crosses over with Haemophilia Awareness Week during the Haemophilia Conference. To mark this, HFA will be launching the National Hepatitis C Needs Assessment Report at the Conference – so that people can "learn the facts" about what it is like to have a bleeding disorder and be affected by hepatitis C in Australia!

HFA has been involved in the advisory group for Awareness Week and would be interested in your feedback about these resources. State and Territory Haemophilia Foundations have samples of the resources, if you would like to look at the range of them or be involved in promoting Hepatitis C Awareness Week. Some Foundations are preparing activities for Hepatitis C Awareness Week. For more information, contact your local Haemophilia Foundation or Hepatitis C Council.

For feedback to HFA, email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au), fax 03 9885 1800 or phone 1800 807 173, or give your comments to your local Haemophilia Foundation. **H**

# CONFERENCE PROGRAM

## THURSDAY 4 OCTOBER 2007

1830-1930 **Cocktail Party and Exhibition Opening**

## FRIDAY 5 OCTOBER 2007

0845-0900	<b>Official Welcome</b> <i>Gavin Finkelstein (President HFA) and Deon York (President HFNZ)</i>		
0900-1030	<b>PLENARY</b> <b>Chair: Dr Scott Dunkley</b>		
	Ethical issues in haemophilia – <i>Dr Ian Kerridge</i> Haemophilia Related Quality of Life – <i>Dr Kathelijn Fischer</i>		
1030-1100	MORNING TEA		
1100-1230	<b>Concurrent 1</b>	<b>Concurrent 2</b>	<b>Concurrent 3</b>
	<b>Inhibitor risk profiling – the care and management of inhibitors</b> <b>Chair: A/Prof John Lloyd</b>	<b>Helping families to manage bleeding disorders better</b> <b>Chair: Clare Reeves &amp; Kelly Brady</b>	<b>Hepatitis C – treatment and care</b> <b>Chair: Dr Michael Pidcock</b>
	Living with an Inhibitor - A personal reflection <i>Michael Prendergast</i>	Understanding pain and needle phobia - comfort and coping strategies <i>Dr Angela Mackenzie</i>	The treatment experience <i>(TBC)</i>
	Predicting inhibitors <i>Dr Jamie Price</i>	Impact of bleeding disorders on the family - tools for advocating for your child and family <i>Colleen McKay</i>	Hepatitis C treatment and care: relevance to haemophilia <i>Prof Geoffrey Farrell</i>
	Role of plasma products in the treatment of haemophilia today <i>Dr Scott Dunkley</i>	Parents & Health Professionals in Partnership - Improving services in Haematology/Oncology Unit at the Women's & Children's Hospital <i>Anne Jackson &amp; Sharyn Wishart</i>	Making decisions about Hepatitis C treatment: what men are thinking <i>Dr Stephen McNally</i>
	Treatment of patients with inhibitors and immune tolerance <i>Dr Chris Barnes</i>		
1230-1330	LUNCH		
1330-1500	<b>Concurrent 1</b>	<b>Concurrent 2</b>	<b>Concurrent 3</b>
	<b>Understanding von Willebrand Disorder</b> <b>Chair: Dr Ross Baker</b>	<b>Youth Matters</b> <b>Chair: Maureen Spilsbury &amp; Robert McCabe</b>	<b>Fitness in children</b> <b>Chair: Gwen Sampson</b>
	Some practical aspects of laboratory testing for von Willebrand Disorder <i>Dr Geoff Kershaw</i>	Building relationships – effective communication and telling partners about bleeding disorders/blood borne viruses <i>Dr Sarah Martin</i>	Fitness and physical activity in children with haemophilia <i>Dr Carolyn Broderick</i>
	Demystifying the classification of vWD and lessons from the Australian clinical trials <i>Dr Ross Baker</i>	Better health and fitness: laying the foundation for positive and independent management of haemophilia <i>Brendan Egan &amp; Janine Furmedge</i>	Strategies to promote healthy participation – overcoming the barriers <i>Wendy Poulsen &amp; Salena Griffin</i>
	A family experience of vWD - <i>Lorraine Bishop</i>	Making the Move: There is planning and there is what actually happens <i>Leonie Mudge</i>	Auckland Islands sea kayak adventure "Bloody Can Do It" <i>Jack Finn</i>
1500-1530	AFTERNOON TEA		
1530-1700	<b>PLENARY - You won't die from laughing</b> <i>Patricia Cameron-Hill and Dr Shayne Yates</i>		
1830	<b>Remembrance Service</b>		
1930	<b>Gala Dinner at Hyatt</b>		

**SATURDAY 6 OCTOBER 2007**

0830-1030	<b>PLENARY</b>		
	<b>Chair: Dr John Rowell</b>		
	Pre-Implantation Genetic Diagnosis and Assisted Reproductive Technology in Haemophilia – <i>Dr Penelope Foster</i> Prophylaxis – when to start/dosing/health economics/joint function – <i>Dr Kathelijn Fischer</i>		
1030-1100	MORNING TEA		
1100-1230	<b>Concurrent 1</b>	<b>Concurrent 2</b>	<b>Concurrent 3</b>
	<b>Complications of Ageing</b>	<b>Impact of Hepatitis C</b>	<b>Women’s Wisdom</b>
	<b>Chair: A/Prof Alison Street</b>	<b>Chair: Steve Waring</b>	<b>Chair: Belinda Burnett</b>
	Vascular disease in haemophilia <i>A/Prof Alison Street</i>	Hepatitis C and young people <i>Vicki Jermyn</i>	Mothers, partners, carers, people with bleeding disorders and carriers of the haemophilia gene <i>Belinda Burnett</i>
	Chronic haemophilic arthropathy <i>Prof John York</i>	Hepatitis C related stigma and discrimination - origins, impacts and responses <i>Helen Tyrrell</i>	Using genetic counselling services <i>TBC</i>
	Falls and balance – from research to practice <i>Marcia Fearn &amp; Prof Keith Hill</i>	Experiences of the bleeding disorders community – HFA needs assessment <i>Suzanne O’Callaghan</i>	Menorrhagia – best practice care and management <i>Dr Julia Phillips</i>
			Management of delivery in carriers & Management of the newborn <i>Dr Sue Russell</i>
			5 minute discussion
1230-1330	LUNCH		
	<b>Concurrent 1</b>	<b>Concurrent 2</b>	<b>Concurrent 3</b>
1330-1500	<b>Scientific and Psychosocial snapshots – new initiatives and progress</b>	<b>Men’s Health - it’s bloke’s business - a session for men to help them better manage their health</b>	<b>Planning and managing best practice care and treatment</b>
	<b>Chair: Dr Scott Dunkley</b>	<b>Chair: Peter Mathews</b>	<b>Chair: Dr John Rowell</b>
	Free Papers Session	Managing the pain of arthritis – what do you do when the drugs don’t work? <i>TBC</i>	Using data for good clinical outcomes (ABDR) <i>Dr Ross Baker</i>
		Dealing with depression <i>Dr Paul Denborough</i>	The NBA four years on - focus on patient needs, achievements and future opportunities <i>Dr Alison Turner</i>
			Safety of haemophilia products - keeping ahead through regulation <i>Prof Albert Farrugia</i>
1500-1530	AFTERNOON TEA		
1530-1650	<b>PLENARY: Conference Closing .....and what about the future?</b>		
	<b>Chair: TBC</b>		
	Panel discussion on future technologies/ gene therapy/ long acting factor products/ novel therapies/ regulatory issues/ community expectations <i>Dr Chris Barnes, Dr Kathelijn Fischer, Prof Albert Farrugia, Deon York</i>		
1650-1700	<b>Closing remarks</b> <i>Rob Christie (VP Finance World Federation of Hemophilia), Gavin Finkelstein (President HFA) &amp; Deon York (President HFNZ)</i>		

# GOOD MANUFACTURING PROCESS - HOW THE TGA PROTECTS YOUR HEALTH

Dr David Graham

The Therapeutic Goods Administration (TGA) regulates all therapeutic goods in Australia through a comprehensive range of measures including ascertaining the efficacy and safety of medicines allowed to be sold in Australia, the licensing of manufacturers and a post-market monitoring and surveillance program that includes laboratory testing of products taken from 'off the shelf' and monitoring adverse reactions to medicines.

Therapeutic goods are medicinal products or medical devices used to diagnose and treat diseases, ailments, problems or injuries in people. Unless therapeutic goods can be reliably manufactured to high standards of quality, they can be ineffective or potentially cause harm to consumers.

A key component of the TGA's overall regulation of medicines and medical devices is the conduct of regular on-site audits or inspections of manufacturing facilities to ensure the manufacturers are compliant with legislated manufacturing principles, including the Code of Good Manufacturing Practice (GMP).

Most industrialised countries have found it necessary to develop good manufacturing practice (GMP) guidelines or codes and the acronym GMP is used internationally to describe a set of principles and requirements which, when followed by manufacturers of therapeutic goods (including all types of medicines), will assure that each batch of a product is safe, reliable and of consistent high quality. A basic tenet of GMP is that simply testing a product after it is manufactured is not sufficient but quality must be built into each batch of product during all stages of the manufacturing process.

## HOW ARE MANUFACTURERS REGULATED IN AUSTRALIA?

In Australia, the Therapeutic Goods Act 1989 requires, with few exceptions, that manufacturers of therapeutic goods hold a licence. It is an offence, carrying heavy penalties, to manufacture therapeutic goods for human use without a licence unless the manufacturer or goods are exempt from this requirement. To obtain a licence to manufacture therapeutic goods, a manufacturer must demonstrate, during a factory inspection, compliance with the legislated manufacturing principles which includes the relevant Codes of GMP and Quality Systems.

Overseas manufacturers of therapeutic goods supplied to Australia must meet an equivalent GMP standard as Australian manufacturers. Sponsors of overseas manufacturers are required to provide evidence of this to the TGA. If acceptable documentary GMP evidence cannot be provided, such as audit reports from another international regulator, TGA auditors (inspectors) will undertake on-site audits in the same manner as those conducted for Australian manufacturers.

Compliance with the Code of GMP in Australia is ascertained by carrying out regular factory inspections. The inspections assess compliance with the relevant manufacturing standard, the conditions specified in the manufacturing licence and compliance with the relevant marketing authorisations. The term 'marketing authorisation' of a therapeutic product means compliance with any other regulatory requirements imposed by the TGA upon product listing or registration in this country.

## INSPECTING THERAPEUTIC GOODS MANUFACTURERS

The Manufacturing Assessment Branch of the TGA carries out the inspection of therapeutic goods manufacturers in Australia. The inspectors travel all over Australia, and occasionally overseas, to inspect factories and establish assurance that the medicines you take have been made in compliance with the expected standards and quality outlined in the Code of GMP and market authorisation. The inspectors are, in essence, 'roving watchdogs' playing an important role in the ongoing protection of public health through their expert assessment of therapeutic goods factories and production standards.

Each inspection involves a detailed examination of the overall operations and procedures of each factory. This includes: a detailed review of all manufacturing steps; assessment of equipment and facilities used to produce therapeutic goods; assessment of cleaning and sanitation processes; review of manufacturing batch records; and assessment of quality control testing of the finished or final product. The TGA inspector may collect product samples during an inspection for testing by the Therapeutic Goods Administration Laboratories.

The inspection concludes with an exit interview during which the manufacturer is provided with a summary of the findings of the audit. This summary is confirmed in writing at a later date by means of an inspection report. The manufacturer is required to respond satisfactorily to the report before the audit is finally completed and a relative compliance rating assigned to the manufacturer. A single inspection may vary from one day for small manufacturing sites to five or six days for larger, more complex factories.

# HEMOPHILIA 2008

XXVIII International Congress of the World Federation of Hemophilia will be held in Istanbul, 1-5 June 2008.

**Why don't you think of going?**

**Why don't you think of submitting an Abstract for Hemophilia 2008?**

**Congress sessions will include:**

Capacity Building – for people working in patient organisations worldwide.

Dental – the latest advances and approaches to dental care in haemophilia patients.

Laboratory Science – quality assurance, laboratory diagnosis, including genetic testing, as well as experiences of laboratory diagnosis in developing countries.

Medical – the latest scientific developments and progress in research, diagnosis, treatment, and care of people living with haemophilia. The medical sessions are not primarily aimed at a lay audience.

Multidisciplinary – psychosocial issues, socio-economic issues, and access to care and care delivery issues of interest to members of national haemophilia organisations, nurses, social workers, and psychologists and to people with haemophilia.

Musculoskeletal – a broad spectrum of treatment and methods of managing musculoskeletal complications of haemophilia.

**ABSTRACTS** – Closing date for Abstracts is 15 December 2007

**EARLYBIRD REGISTRATION** – Closing date for Earlybird Congress Registration is 31 October 2007

Visit [www.hemophilia2008.org](http://www.hemophilia2008.org) for further information. 



If a company does not comply with the Code of GMP, potentially placing consumers at risk, the TGA inspectors have the authority to impose additional conditions on the licence or restrict the licence if there is a possibility or evidence of sub-standard and/or unsafe products being manufactured. In extreme cases, the inspectors can issue instructions for production to cease immediately. The TGA can suspend or revoke a manufacturing licence. It is important to note that there have been no recent examples of this needing to occur.

Australian companies that manufacture therapeutic goods are subject to regular re-audits or re-inspections of their facilities to ensure that they continue to comply with the Code of GMP. The TGA decides the frequency of this on a case by case basis. Key factors which are taken into account when determining the frequency of on-site inspections (audits) include: the company's track record, such as product recalls and complaints; adverse drug reaction information; and the GMP compliance rating from the previous TGA inspection.

TGA inspectors are highly qualified and experienced in medicines and medical device manufacturing. Many have previously worked in the pharmaceutical and medical device industries before joining the Australian Public Service to perform these important safeguard duties.

## **WHAT ARE THE RESPONSIBILITIES OF COMPANIES WHO MAKE MEDICINES?**

Each company holding a TGA manufacturing licence must manufacture medicinal products so as to ensure they are fit for their intended use, comply with the regulatory requirements, are manufactured in a GMP compliant facility and do not place consumers at risk due to inadequate safety,

quality or efficacy. Attaining this quality objective is the responsibility of senior management and requires the participation and commitment of staff in many different departments and at all levels within the company, as well as the company's suppliers and distributors.

To reliably and consistently achieve the quality objective there must be a comprehensively designed and correctly implemented system of Quality Assurance incorporating Good Manufacturing Practice. It should be fully documented and its effectiveness monitored. The Quality Assurance system should be adequately resourced; this includes having competent personnel and suitable manufacturing premises, equipment and facilities. There are additional legal responsibilities for the holder of the manufacturing licence. These are routinely checked by the inspectors during their on-site inspections. 

# THE VISION AND LEADERSHIP AWARDS

The Haemophilia Foundation Australia Vision and Leadership Awards were established in 2007 to provide people affected by bleeding disorders with an opportunity to undertake an education activity or project to enhance their personal development or career, or develop skills for leadership and participation in the bleeding disorders community.

The Awards are generously supported by Wyeth through a pledge of up to \$10,000 each year for the Awards. The Vision and Leadership Awards are administered solely by HFA under a Memorandum of Understanding with Wyeth.

The assessment panel included Craig Goodhand, Manager Training & Organisation Development, Elders Limited, from Adelaide; Chris Bonnor, who has wide experience as a principal of secondary schools in NSW; Gavin Finkelstein, HFA President; and Sharon Caris, HFA Executive Director.

The Awards are available to people of all ages and two specific categories have been established to encourage young men and women aged 15-25 and adults aged 26 yrs and over who have a bleeding disorder to apply.

Applicants were encouraged to consider what would make a

difference to their life and seek assistance through this award opportunity to achieve success or reach a new goal or objective.

A large number of applications were received for the 2007 funding round, and unfortunately many excellent projects could not be funded.

"The Awards are an exciting new initiative offering a great opportunity for people affected by bleeding disorders to achieve new goals and HFA is grateful to Wyeth for its support", said HFA President Gavin Finkelstein recently. 

## CONGRATULATIONS

<b>Michael Cerantola</b>	Work training to enhance qualifications
<b>Justine Mamootil</b>	14th Australian & New Zealand Haemophilia Conference
<b>Peter Mathews</b>	Further education
<b>Robert McCabe</b>	WFH Congress, Istanbul
<b>Martin Raspin</b>	Further education to enhance qualifications
<b>Dale Spencer</b>	14th Australian & New Zealand Haemophilia Conference



# THE VISION AND LEADERSHIP AWARDS

The Consumers' Health Forum of Australia provided permission to reproduce Online Review – The new consumer section of the PBS website by Elizabeth Grant, which was first published in "The Australian Health Consumer" Issue 1 of 2006-07. Dr Grant was appointed by the Minister to the National Drugs and Poisons Scheduling Committee. She contributes to the Consumers' Health Forum through the medicines email list and CHF consumer representative workshops.

# ONLINE REVIEW- THE NEW CONSUMER SECTION OF THE PBS WEBSITE

Dr Elizabeth Grant

- Do you want more information about the Pharmaceutical Benefits Scheme (PBS) and the medication you have been prescribed by your medical practitioner?
- Do you want to know about the effects these medicines will have?
- Would you like to know how much you can expect to pay for your prescription?

All these questions and many more are answered in the consumer section of the Australian Government Department of Health and Ageing Pharmaceutical Benefits Scheme website: [www.pbs.gov.au](http://www.pbs.gov.au).

Consumer advocacy and the Australian Government's decision to provide more transparency in the PBS have led to a website that has succeeded in providing an 'easy to use version of the Schedules'. The information is updated regularly and includes changes to the drugs listed in the Schedule.

The website is incredibly extensive and answers any questions which consumers may raise, mostly in language which is easily understood. The search menus are comprehensive and simple to use and information is readily available about any medicine you may wish to find.

Information about each medicine is presented in a tabular format, searchable by simply keying in the name of the medicine – either the brand name or the medicine name. Information includes the various brand names of the medicine name, the source (ie the Schedule) and the body system (this is the term that is used to describe the body's anatomy functions and medical conditions that are grouped together. These World Health Organization groupings are used in the Schedule and referred to as Body Systems).

Where available, Consumer Fact Sheets are listed and can be downloaded in PDF format. These are identical to those supplied by the pharmacists when consumers are prescribed a new medication. The table also provides the pricing structure for the product for each category of consumer, as well as the amount paid as a Government subsidy for each medicine. A list of manufacturers indicates those medicines which are included in the Schedule from each pharmaceutical company. As well, new and deleted items are listed under brand names as well as the medicine name.

The Schedule is updated each month and changes are clearly identified in a separate section covering new, amended and deleted items. Changes are effective on the first day of each month.

The website also has a comprehensive section about the PBS itself, with information about the PBS, who is eligible, the Repatriation Pharmaceutical Benefits Scheme, the Dental Scheme, eligibility for concessions, patient fees and charges including a detailed item on co-payments, and the Safety Net.

A handy list of PBS contacts is included, as are the schedules of pharmaceutical benefits back as far as August 2003.

A valuable section deals with adverse drug reactions and gives details of methods of reporting such events. This very comprehensive section includes frequently asked questions and will assist consumers who are not certain about what to do in the event of an adverse drug reaction. It also identifies the data required for such reporting. This information is actually located on the Therapeutic Goods Administration (TGA) website which is linked to the PBS site. As well, there are links to other information on the TGA site, including the travellers who may be seeking specific travel-related medical information.

This website answers the calls from consumers over many years for readily available information about medications supplied under the Pharmaceutical Benefits Scheme, particularly in relation to supply, pricing, benefits and risks. It is an excellent site, and I recommend consumers take the opportunity to use it extensively as an information resource. **H**

The bleeding disorders community relies on a team of people to actively work to be aware of the needs of the community, to flag emerging issues, and to represent the community to other community organisations, governments and the more general Australian community. Whilst just a few of these people are paid employees of HFA or State/Territory Haemophilia organisations, most are volunteers who work in different ways on behalf of individuals with bleeding disorders and their families in Australia and overseas. In the first of a series of articles about the people who undertake this valuable work around the country we invited Beth Large from Queensland and David Bell from Western Australia to describe their motivation to volunteer their time and expertise to the benefit of the community. Volunteering can be a win-win situation – it sometimes takes a lot of time and effort – especially for people with already busy and complex lives, but it also brings much satisfaction, new connections and enormous personal benefits. Beth Large is a Committee of Management member of Haemophilia Foundation Queensland and one of the HFQ Council Delegates to HFA.

# VOLUNTEERING FOR HFQ

Beth Large

How did I become a volunteer for Haemophilia Foundation Queensland? After my son was diagnosed with severe haemophilia A we were all quite shocked. I am the youngest of five children, my mother had 14 siblings and my maternal grandmother came from a family of eight children. My siblings and I were all pretty well connected to our aunts and uncles and cousins. Our Christmas and family gatherings were huge. So we knew that no-one had haemophilia or was a carrier. I wasn't surprised to find out that I was the carrier and the whole process would have started at my conception. Of course, there was no one to blame; my mother had just passed away the same week my son was diagnosed and my father had died 10 years before. So my attitude was a simple "Oh well ... let's just deal with IT!!" Like everyone, you find as much information as you can - from health professionals, information brochures and the internet (what would we have done without the net!). My husband Andrew and I realised it was manageable and that there could be a whole lot of worse situations.

I suppose it was because my attitude was extremely positive that a health professional encouraged me to become involved with HFQ. It was probably only 2-3 months since our child was diagnosed that I was elected to the committee for HFQ.

The previous committee was going through some changes and needed a few new faces – I was one! I thought that if I could become involved it would give me a better understanding of the processes of living with haemophilia. How privileged we really are – thanks to past thinkers and planners we don't pay for our clotting factor or our care. It blew me away that at the clinic there would be a team of four professional medical staff caring about our son's health. That the level of care was outstanding. That there were counsellors who concentrated on how the whole family would cope with haemophilia, not just the patient. That everything was at a personal level and we were not just another number.

That was three years ago and I'm still on the Committee. I even have a title, "Secretary". But nothing else has changed: we still get outstanding care; we still have four medical professionals who sit in one room together to discuss our son's health. I am still aware of how lucky we are, but the one thing I have learned is how I want to keep it this way. For haemophilia not to fall off the agenda of governments and medical researchers and for us to still have a designated medical clinic. For us to be a voice! Even though a small voice, we need to be a strong voice for research and support. Basically that's the reason I'm still on our committee; to make sure we don't fade into the background and become complacent about what we have achieved through the diligence of our forebears. It may sound cynical – but you just never know – governments change and their priorities change.

My work with HFQ doesn't take much of my time – a meeting a month, a few signatures here and there, a few ideas, turn up to a few events a year. And for that I've learnt a lot, not just about haemophilia but how the governments fund us and how other States work. And there is a bonus in meeting a few other families in similar situations. Some of these families will be friends for a long, long time.

What I personally would like to have for the Foundation in the future is a strong team, not always the same team, but a team that is representing our community well and is prepared for the changes that may come in the future. Because I think there will be a lot of changes in the near future and these will affect my son.

I don't intend to be on this committee for my entire lifetime. I would like to hope that other people also realise how lucky we are and want to work towards keeping it that way. But at the moment I'm eating pizza and having a pretty good time! **H**



# A STATE AFFAIR



David Bell

I was asked to write an article for *National Haemophilia* on my "relationship" with my State foundation, Haemophilia Foundation Western Australia, and why I volunteered.

I am 34 years old and have severe haemophilia, the obligatory joint issues and the accompanying viral baggage. I am married and have a young family, but no longer work due to the impact on the joints that haemophilia has on the "older" generation. I keep busy with the family, sharing the load with the household chores and playing around with the little projects I always seem to have on the go in the shed.

I have been involved in HFWA since 1998 when I was starting to mature (yep it took a while). I felt it was about time I joined the foundation. As I missed a lot of school in my childhood due to long hospital stays, I was not the most academic student and had looked for a trade style career. In the early days I was just a committee member and self confessed seat warmer, and a bit in awe of the whole meeting process. As I had never been involved before it was all a bit scary.

As time went on I became more comfortable and more confident, and as my confidence grew my participation increased. The standard joke on our committee is our newsletter should be renamed the Bell chronicles, as I am always doing a few articles for each issue. So perhaps I have found my niche!

Since joining HFWA my personal health knowledge and wellbeing has increased due to interaction with others on the committee and the peer support functions it provides.

As the years have gone by I have moved up to become one of HFWA's State delegates to HFA and I am now the Vice President of HFWA.

I find being on the HFWA committee a challenge personally and get a lot out of it. I have proven to myself that even though I lack the "degrees" I can fill the role.

Because I no longer work, I can volunteer my time to the foundation, and can represent HFWA at different forums. I enjoy these as it gives me chance to interact with other people and hear or share their views on many varied topics, and fortunately, not always health related. This is not always possible when you are no longer involved in the workforce.

I enjoy being involved with HFWA, and it is very satisfying to be able to achieve so much as an organisation. In WA the foundation worked with others to secure funding for a counsellor, access to Royal Perth Hospital theatres for an orthopaedic surgeon, and we are dedicated to maintain and increase haemophilia care for the community we represent in WA.

And being on the HFA Council is similar, but it is on a bigger scale. As States we join together under the HFA umbrella, and look what a uniform group can achieve. One example is the role of the community in getting universal access to recombinant clotting products and safer plasma derived products.

I feel that any foundation is only as strong as its membership, and the membership needs to support the management committee. At the end of the day these committees are there for the best interests of our community, and to advocate on matters that concern us or our family's health issues.

To use one of the sayings from a WA committee member, 'the foundations evolved from a tragedy'. Heaven forbid we don't have another, nor have the need to re-establish the foundations if something unexpected did occur. We should support what we have now and strive to build a stronger future.

If you want to have input into the future, jump on board your State's foundation.

Personally, as I have said above, I believe I have got and continue to get great benefit from my experience with HFWA and on the HFA Council, and on reflection I even have some regret that I didn't become involved earlier.

When I first started writing this article, Tammy walked past and read the heading, the first few words of the second line, and then got a bit worried about what I had written about "the relationship". She was reassured when she saw what it was about! I have thrown the keyboard to her so she can make her observations about my involvement with the haemophilia community.

## And.....from Tammy Bell

I have been with Dave for 16 years, married for 11 of those. For Dave, being on the HFWA committee has been great for him. I have seen his confidence grow over the years when it comes to him standing up in front of a group of people and just in general. As Dave has already mentioned he benefits because he can test his skills and work on his shortfalls.

I think it has been good for Dave to participate because he brings his own down-to-earth views to the committee.

I am involved in a different way – and attend some of the peer support activities hosted by HFWA. I find these very beneficial and strongly believe in the importance of the HFWA to represent its members when it is needed.

I am glad that Dave and all the other committee members give up their time to represent the whole bleeding disorders community. And last but not least, when he is busy with the foundation he is out of my hair!!!

# JOINTS AND MUSCLES

Lynette Hing, who is a physiotherapist at Starship Children's Hospital in Auckland and a member of the Australian and New Zealand Physiotherapy Haemophilia Group (ANZPHG), has adapted an extract from Karli Joll's booklet "Physiotherapy and Haemophilia". Karli is also a member of ANZPHG and works at Waikato Hospital, Hamilton, New Zealand.

## JOINT AND MUSCLE CARE

Joint and muscle bleeding episodes may occur spontaneously (without an apparent cause), or as a result of trauma (injury). It is important to distinguish a bleeding episode and treat it quickly with factor replacement. If necessary, it is sometimes recommended to have factor replacement therapy prior to sporting or other activities. Check with your haematologist.

During a bleed and after factor replacement use of the RICE protocol is recommended:

- Rest: the affected part for 24 hours or until the bleeding has stopped. Padded splints, slings and crutches can be used.
- Ice: If pain and discomfort are a real problem you can use crushed ice wrapped in a damp towel, or a packet of frozen vegetables applied over the area. Apply for 10 minutes only, no more than every two hours. Check the skin regularly as ice burns can occur.
- Compression: Use tubigrip (a stretchy circular bandage) to help control the amount of swelling – it should be firm but not constrict the blood flow to the limb. Your physiotherapist or nurse can provide this.

- Elevation: Whenever possible in the first 24 hours, rest the limb up high on a pillow, especially when icing. This helps to control the amount of swelling.
- Once the bleed has settled, (usually within 24 hours after factor replacement) the affected part can be gently exercised. This is best done in the following way:
  - Start with static muscle work. This is when you tighten the muscles around the affected part without actually moving the joint.
  - Progress from static muscle work to movement work. This is when you move the joint through the entire range of movement.
  - If there is any residual weakness, then build up the muscle power by doing strength work. Start with easily resisted exercises first, and then gradually make them more demanding. (Joints with weaker muscles are more susceptible to bleeds, either spontaneous or following trivial injuries.)

It is important that if the bleed does not settle completely following the above management, that advice and/or treatment is sought from a physiotherapist. If swelling does not settle completely it can be a trigger for more permanent and disabling damage.

## JOINTS

The most commonly affected joints in haemophilia are the 'hinge' joints such as the knee, elbow and ankle. The ends of the bone are lined with cartilage which is smooth and glassy and acts as a 'shock absorber'. Repeated bleeds can cause joint damage to the cartilage and sometimes even bone can be worn down. Therefore it is really important to firstly try and prevent these joint bleeds from happening (eg prophylactic treatment, appropriate sports), and secondly to manage the acute symptoms as effectively as possible. **H**

## Exercises for the knee (and leg)

## EXERCISES FOR JOINTS AND MUSCLES

The following are some examples of knee exercises for the rehabilitation of bleeding episodes in people with haemophilia. It should be noted that if you or your child has specific joint or muscle problems they should be assessed by a physiotherapist and given a comprehensive and individualised exercise program.

Remember the principles: Rest initially, then static exercises, then gentle movement exercise, and lastly strengthening exercise. NEVER force a joint.

Exercises should be carried out regularly several times a day, and each exercise should generally be repeated 10 times. Do the exercises slowly aiming for full movement or contraction of muscle.



1. Static: Lying on your back with legs straight. Push the back of the knee down into the bed, tightening the thigh muscle, while pulling the ankle up. Hold 5 seconds.

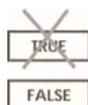
An apology is extended to Matthew Beard, author of the following article, which was published in the June 2007 edition of "National Haemophilia", No 158. Unfortunately the published article contained several formatting errors. The article is reprinted below in its correct format.

Most people get back pain, everyone has an opinion, but what are the simple facts? Matthew Beard is a physiotherapist who has clinical involvement with haemophilia and spinal clinics at the Royal Adelaide Hospital. He is a member of the Australian and New Zealand Physiotherapy Haemophilia Group.

# BACK PAIN MYTH BUSTERS

Matthew Beard

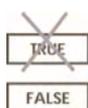
## X-RAY – EVERYONE SHOULD HAVE ONE?



- Findings described on X-Ray reports are not necessarily related to symptoms
- X-Rays do not necessarily assist in diagnosis

**Complex tests and scans are not always necessary**

## SLIPPED DISC – DO YOU NEED SURGERY?



- Few people require surgery
- Bulging discs are common and do not always cause pain

**Surgery is a last resort - always seek a second opinion**

## WANT TO KNOW MORE? FOR MORE INFORMATION:

[www.informedhealthonline.org](http://www.informedhealthonline.org)

[www.nhmrc.gov.au](http://www.nhmrc.gov.au)

[www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)

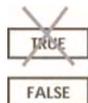
[www.cochrane.org](http://www.cochrane.org)

## DISCLAIMER

The author has endeavoured to ensure the information is accurate, however makes no representation or warranty to this effect. **H**

Illustrations have been adapted from Microsoft clip-art.

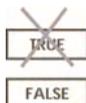
## BED REST, IS IT THE BEST THERAPY?



- Too much will delay recovery
- Routine activities should be continued where possible

**Exercise is best for both prevention and treatment of low back pain**

## DOCTORS – SEE ONE IMMEDIATELY?



- Most cases improve quickly
- The best treatment is to keep active
- Simple pain tablets can be useful

**Seek immediate medical attention if experiencing leg weakness or loss of bladder/bowel control**



2. Movement (small range) and Strength: With your knee slightly bent over a roll (eg a rolled up towel): lift the foot up and straighten the knee. Lower slowly.

3. Movement: Lying on on your tummy, bend and straighten your knee.



4. Movement: Sitting on a chair, straighten your knee then bend slowly.

Strength: Repeat exercises 3 and 4 and make them harder by tying a small weight to the ankle such as a bag of rice or a sandbag.

# CALENDAR



## 14th National Haemophilia Conference

Canberra 4-7 October 2008  
ph 03 9885 7800  
fax 03 9885 1800  
email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)

## National Hepatitis C Awareness Week

1-7 October 2007  
ph 02 6232 4257  
[www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)

## Haemophilia Awareness Week

7-13 October 2007  
ph 03 9885 7800  
fax 03 9885 1800  
email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)



## XXVIII International Congress of the World Federation of Hemophilia

Istanbul, Turkey, 1-5 June 2008  
[www.wfh.org](http://www.wfh.org)

## Corporate Partners

Haemophilia Foundation Australia (HFA) values the individuals, Trusts and Corporations which donate funds to support our objectives.

Among our valued donors are our Corporate Partners who provide unrestricted grants to HFA to support our programs:

**Baxter**

**CSL Bioplasma**



**Wyeth**

## 20th Annual ASHM Conference

Perth 17-20 September 2008  
ph 02 8204 0770  
fax 02 9212 4670  
email [conferenceinfo@ashm.org.au](mailto:conferenceinfo@ashm.org.au)  
[www.ashm.org.au/conference](http://www.ashm.org.au/conference)

## 6th Australasian Viral Hepatitis Conference

Brisbane 20-22 October 2008  
ph 02 8204 0770  
fax 02 9212 4670  
email [conferenceinfo@hepatitis.org.au](mailto:conferenceinfo@hepatitis.org.au)  
[www.hepatitis.org.au](http://www.hepatitis.org.au)

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